Palliative Care Information and Resources during COVID-19

PURPOSE

This document provides information, advice and links to resources to support health, social care and third sector partners to respond to the global COVID-19 pandemic in relation to palliative and end of life care.

It includes links to local and national guidance on the palliative care management of COVID-19 in Wales. The focus is on guidance and advice that will help achieve dignified and compassionate care at the end of life for adult patients who would not benefit from life support, or where this has not been successful and where their condition has deteriorated as a result of COVID-19.

CONTENTS:

1. Guiding Principles – Moral and Ethical Framework

A newly established COVID-19 Moral and Ethical Advisory Group Wales (CMEAG-Wales) will consider and advise the Chief Medical Officer and Welsh Ministers on moral and ethical issues as a collective response to COVID-19 across public services in Wales. The advisory group has developed a framework of values and principles, endorsed by the Minister for Health and Social Services, the Deputy Minister and Chief Whip and the Minister for Housing and Local Government for healthcare delivery in Wales.

https://gov.wales/coronavirus-ethical-values-and-principles-healthcare-delivery-framework-0

The Mental Capacity Act and the Deprivation of Liberty Safeguards (DoLS) remain fully in place. Guidance on the implementation of DoLS during the COVID-19 pandemic has been produced:

https://www.gov.uk/government/publications/coronavirus-covid-19-looking-after-people-who-lack-mental-capacity

Where a best interests decision has to be taken on behalf of a person, it is important to ascertain whether a lasting power of attorney for health and welfare decision is in place and registered with the office of the public guardian, whether there is an advance decision to refuse specific treatments and all information available about a person's wishes and preferences should be taken in to consideration.

2. Specialist Support -The role of Specialist Palliative Care

Specialist palliative care teams and services are uniquely positioned to support their NHS Wales colleagues to care for those with end of life care needs through this unprecedented palliative care emergency, when they will rely more than ever on palliative care and end of life expertise. While services face a challenging time, those with such expertise will be on hand, building the skill capacity and confidence in generic teams to effect good end of life care in all settings.

Health boards have recognised the contribution of the specialist palliative care teams and services to this crisis and are maximising their skills and knowledge in their COVID-19 response plans. Field hospitals and additional facilities are being established to meet additional need across Wales. With specialist palliative care as a core component, they are providing additional end of life care training, specifically for these new areas, and in some instances have a constant staff present on site.

Specialist palliative care services have supported the COVID-19 response across Wales in a number of ways, these include:

• Producing a series of guidance, which can be adapted to fit local service provision;
• Training/cascading training for generic teams/redeployed/bank staff for EOL care and symptom management;
• Building confidence and resilience for the provision of EOL care in these teams;
• Triaging of patients and referrals including COVID-19 ward-rounds;
• Support of nurse-led units and field hospitals for COID-19;
• Supporting arrangements for verification of death for health and social care professionals;
• Timely responses and solutions to shortages of drugs and devices;

- Workforce planning for services to support 24/7 – to extend the reach of advice.

There may be changes in the way that specialist services deliver care during the COVID-19 Pandemic – please check with your local services for more information.

3. Voluntary Hospices

Hospices are the bedrock of NHS-commissioned non-hospital specialist palliative care in some parts of Wales. They are central to the delivery of care and recognised by the public as beacons of compassionate care. Their ability to adapt and change, often at speed, to meet local need will be paramount to providing wider support to those affected by the COVID-19 pandemic and later as we address the healing process in our community.

Hospices have been involved in the local COVID-19 planning groups and are looking at new ways to support this palliative care emergency. At a time, when they will have seen reductions in financial contributions that enable them to provide bespoke hospice provision, they also face challenges such as maintaining services when staff and volunteers are self-isolating. Yet the pandemic has already seen an increased service demand, coupled with increased levels of COVID anxiety in their current caseload.

Additional Welsh Government funding provided to support hospices will enable them to continue to deliver essential clinical services and they will continue to work collaboratively with health boards to address local need. Web link refers:

https://gov.wales/minister-announces-ps63-million-hospices-wales-during-covid-19-outbreak

4. Frameworks for Care

Due to the nature of COVID-19 and the often-rapid deterioration at the end of life, systems are in place to support rapid escalation of care, including referral, triage, prescribing, access to drugs, and supportive care plans with access to 24-hour support for symptom advice.

a) Clinical Guidance

Professional clinical bodies have produced national guidance for use during COVID-19, referenced within this document. Health boards should use this guidance alongside their own COVID-19 strategic plan and other supporting documents. Information is changing rapidly as new evidence emerges, with regular checks needed to ensure the latest version is in use. Updates on guidance and additional information can also be found at Wales Palliative Care:

https://www.wales.pallcare.info/index.php?p=sections&sid=42

b) Advance/Future Care Planning & Treatment Escalation Plans

Advance care planning is critical to ensuring that people who are or who may become palliative due to the pandemic have an opportunity to discuss their wishes about their personal care and treatment on a case-by-case basis. The All Wales Advance/Future Care Planning group led by Dr Mark Taubert, working with the national clinical lead for End of Life Care, Dr Idris Baker, have produced guidance to support decision making during COVID-19, along with additional supporting guidance. The following link shares access to resources

and forms for patients and healthcare professionals, aiming to provide a One Wales sharing and involving approach.

http://www.wales.nhs.uk/researchandresources/publications/nhswalesadvancefuturecareplans

The General Medical Council and Nursing and Midwifery Council have published a joint statement on advanced care planning. The statement reiterates that the COVID-19 pandemic does not negate the need for healthcare professionals to have personalised discussions around end of life care planning including whether or not to issue a DNACPR.

https://www.nmc.org.uk/news/news-and-updates/statement-advance-care-planning-dnacpr-gmc-nmc/

Additional information to assist decision-making can be found at:

http://advancecareplan.org.uk/

https://gov.wales/coronavirus-ethical-values-and-principles-healthcare-delivery-framework

An All-Wales Treatment Escalation Plan (TEP) has been agreed for use during COVID-19. It is not legally binding but provides guidance and structured handover of decisions and conversations that have been held, and can reference much longer annotations in the contemporaneous notes (Please note that NHS intranet access is required).

http://www.wales.nhs.uk/researchandresources/publications/nhswalesadvancefuturecareplans

HIW/CIW have also issued a joint statement on advance care planning:

https://careinspectorate.wales/200421-joint-statement-hiw-personalised-advance-care-planning-wales

c)   **All Wales DNACPR policy during COVID-19 Pandemic**

There has been an addendum to the DNACPR policy (Version 3 2017) for use during the pandemic. This following link includes the recent emergency update regarding the existing all Wales DNACPR policy during the outbreak.
http://www.wales.nhs.uk/researchandresources/publications/sharingandinvolvingaclinicalpolicyfordonotattemptcardiopulmonaryresuscitationdnacprforadultsinwales

The Chief Medical Officer and the Chief Nursing Officer have issued a joint letter to all health boards to ensure there is clarity around ethical decision making for people with any protected characteristic under the Equality Act 2010. This includes age, vulnerability, physical or learning disability, autism, other life-long illnesses, conditions such as cerebral palsy, enduring mental health conditions and substance misuse problems. I have attached the web link to the letter which also contains links to other relevant information:

https://gov.wales/decisions-do-not-attempt-cardiopulmonary-resuscitation-dnacpr-age-disability-and-long-term

RCGP Cymru and BMA Cymru have also published advice on supporting patients most vulnerable to coronavirus on 'Having sensitive conversations and Advance Care Planning'. This can be accessed at:

https://www.rcgp.org.uk/covid-19/-/media/071B53AEEE20455A9669EDC1F66B2FCB.ashx

d) **Access to symptom control medication for Palliative and end of life care**

A primary and community care COVID-19 Framework/Pathway for Wales for the pre-hospital management of COVID-19 infection has been produced. The purpose of this framework is to support primary care, community and paramedic colleagues in decision making regarding the management of patients presenting with suspected or actual COVID-19.

The framework provides a consistent approach to the management of patients during the COVID-19 pandemic and to deciding on place of care, and is aligned to the all Wales secondary care guidance. It also complements Public Health Wales primary care guidance and will support care in community settings, including residential homes and nursing homes. This is important for those people for whom home is the preferred place of care in these circumstances, or for whom it is in their best interests to be cared for at home if they lack capacity to decide, so long as care can be provided there. Provision of drugs for symptom control is particularly urgent in severe COVID-19 infection where some patients develop distressing but treatable symptoms very quickly.

http://www.primarycareone.wales.nhs.uk/sitesplus/documents/1191/FINAL%20Community%20Covid%20Framework%20and%20Pathways%2020200330%20v3.pdf

NICE have also issued COVID-19 rapid guideline: managing symptoms (including at the end of life) in the community NICE guideline [NG163]. The purpose of this guideline is to provide recommendations for managing COVID-19 symptoms for patients in the community, including at the end of life. It also includes recommendations about managing medicines for these patients, and protecting staff from infection.

https://www.nice.org.uk/guidance/ng163/chapter/3-General-advice-for-managing-COVID-19-symptoms

The Association for Palliative Medicine (APM) has produced symptom control guidance which is being updated frequently in light of experience in the UK and elsewhere as reported by clinicians and in academic journals. Clinicians are encouraged to consult the most recent version, found on the homepage at:

https://apmonline.org/.

If symptom control drugs, and syringe drivers which are used to administer them for some patients, are in unusually high demand, supplementary guidance on alternatives may be produced in consultation between experts in the relevant clinical and logistics disciplines in Wales and elsewhere. There has been some preparatory work on this. It will be finalised according to the situation in which it is to be used, released as bespoke short-term guidance, and revised according to the changing availability of these medicines.

Measures are being considered to minimise delays in medications being supplied and administered.

Before and during the pandemic, some families have asked to be able to give drugs by injection at home rather than rely on a nursing visit. Support for them to do this when that is there and the patient's preference is being made possible by implementation of guidance and policy arising from the CARiAD (Carer Administration) study. This includes training of lay carers, supply of equipment and information, and phone support to help decide what is needed.

https://www.wales.pallcare.info/files/docs/CARiAD%20Package/A%20-%20CARiAD%20for%20Covid-19%20policy%20v1.0%2020%20March%202020.pdf

A new NHS Wales Interim End of Life COVID-19 Medicines Service will provide access to a "medication box" of an agreed list of medication – a Just-In-Time Emergency Medication Pack (JEMP) – through a single point of access to supplement the normal service, with a focus on coverage of out-of-normal working hours during the COVID-19 pandemic.

The Health Courier Service Wales (HCSW) will manage a single point of contact (SPOC), and direct the JEMP request to the most appropriate EoL pharmacy hub (EPH) situated at one of five sites around Wales.

The hub will supply a patient with a JEMP in the following circumstances:

1. Out of hours where there is a "need" to supply irrespective of where the patient resides at that time e.g. community or field hospital.
2. During Normal Working Hours if local service provision cannot access the required medicines in a timely manner.

https://www.awttc.org/covid-19-eol-medicines-service

Alternative Drugs for use in shortages

Information on priority medicines for use in palliative and end of life care during a pandemic has been developed by APM, the Royal College and General Practitioners, the Association of Supportive and Palliative Care Pharmacy and Hospice UK and is available at:

https://apmonline.org/wp-content/uploads/2020/04/priority-meds-for-end-of-life-care-290420-final-2.pdf.

Medicines including those used in end of life care occasionally come into short supply. Information about medicine shortages is published on the Welsh Government/Public Health Wales Public Health Alert website at:

https://www2.nphs.wales.nhs.uk/contacts.nsf.

Please also be aware of local updates on medicine supply issues.

The Chief Pharmaceutical Officer has issued a Welsh Health Circular supporting the limited reuse of end of life medicines in care homes and hospices, in exceptional circumstances. This guidance provides NHS organisations with advice to support establishing arrangements that ensure timely access to end of life medicines for patients in care homes and hospices in particular through the reuse of medicines prescribed for one patient by others. The guidance does not provide for care homes to obtain stocks of medicines unless

they have the appropriate licenses in place. This guidance applies only during the COVID-19 pandemic and can be accessed at:

https://gov.wales/reuse-end-life-medicines-hospices-and-care-homes-during-covid-19-whc2020008

Welsh Ambulance Service Trust – Just in Case Medication.

Under these exceptional circumstances, in order to support patient care and the implementation of the Community COVID-19 Framework, WAST paramedic staff will have access to "just in case" medications to manage end of life symptoms. In order to administer these medications, paramedics require verbal authorisation from an authorised prescriber e.g. a GP.

5.   Use of Digital Technology

The NHS Wales Video Consulting (VC) service is a video consultation service rolled out by Welsh Government to offer healthcare services in a safe and secure way to see patients via a video appointment, rather than seeing them in-person. The VC service is delivered via a communication platform called 'Attend Anywhere'. Some areas are conducting virtual video assessments using the 'Attend Anywhere' web-based platform to support assessments and extend the reach of specialist palliative care advice.

https://digitalhealth.wales/tec-cymru/vc-service?section=30

Weekly ECHO (extension of community healthcare outcomes) video links for voluntary/third sector staff are available through Hospice UK on a UK-wide basis to share and inform practice. Project ECHO is a not-for-profit movement to improve care by gathering a community of practice together for learning and support with the goal of improving decision-making by collaborative problem solving.

6.   Caring at Home

Services provided in the community by primary care teams, district nursing, hospice at home teams and social care teams will be available to address the increased need during COVID-19, sadly many of those who will be caring for loved ones at home may find the situation change rapidly when professional support is not on hand. While clinical teams supporting such patients and their carers will be able to offer advice and support, it is useful to have written information to reduce anxiety and offer practical tips on caring at home. Useful advice often provides reassurances and can make the difference in reducing care breakdown. The Bevan foundation have published advice produced by Professor the Baroness Finlay of Llandaff entitled *'Caring for your dying relative at home with COVID-19'.*

https://www.hospiceuk.org/docs/default-source/echo/covid-19-echo/covid-19_care-at-home_guide_final.pdf

7. Care Homes

Support for care homes residents with palliative care needs will be maintained, however the principles within the '*Caring for your dying relative at home with COVID-19*' can also be applied in the care home setting.

Public Health Wales have issued guidance on the admission and care of residents during COVID-19 Incident in a residential care setting in Wales. This guidance is intended for Public Health Wales, local authorities, local health boards and registered providers of care homes or supported living arrangements where people share communal facilities.

https://phw.nhs.wales/topics/latest-information-on-novel-coronavirus-covid-19/information-for-healthcare-workers-in-wales/admission-and-care-of-residents-during-covid-19-incident-in-a-residential-care-setting-in-wales/

Information on visiting COVID -19 patients at the end of life must be available, outlining any potential risk and what is expected of visitors during their stay. It is a basic human right to be able to have those you hold dear, with you at the end of life. The long established practice of offering relatives an opportunity to visit as death approaches to say goodbye, can, not only comfort the dying, but also assist those left behind with the grieving process. Where at all possible, without compromising the safety of the public and professionals caring for the patient, this principle should be upheld during COVID-19.

Care Inspectorate Wales have published frequently asked questions for care providers and staff across Wales during COVID-19:

https://careinspectorate.wales/coronavirus-covid-19-frequently-asked-questions-faqs

8.   Spiritual Care and Support

Most members of the public will have little experience of caring for a dying relative or friend and may feel ill prepared and anxious. This is compounded by the current restrictions on visiting patients dying of COVID-19, after death arrangement and funeral services.   While NHS Wales will do everything, it can to provide the care and support; patients, family and carers are likely to benefit from a holistic approach, regardless of religious belief. The following links provide a range of supportive advice and toolkits through this difficult time.

https://www.goodlifedeathgrief.org.uk/content/support_with_covid19/

https://www.mariecurie.org.uk/professionals/palliative-care-knowledge-zone/proving-good-quality-care/covid-19#public
http://www.cytun.co.uk/hafan/en/home/

https://humanism.org.uk/2020/03/23/new-funeral-guidelines-issued-live-streaming-delayed-memorials-and-new-gestures-to-replace-hugging/

http://callhelpline.org.uk/

9.   Support for Professionals

A free mental health support service for doctors has been expanded to provide support and advice for all front-line NHS Wales staff during the COVID-19 pandemic.

https://gov.wales/mental-health-support-scheme-doctors-extended-every-frontline-healthcare-worker-wales

Social Care Wales has developed a resource to support the health and well-being of social care workers during the coronavirus pandemic:

https://socialcare.wales/service-improvement/health-and-well-being-resources-to-support-you-during-the-coronavirus-covid-19-pandemic

The mental health charity MIND have developed a tips and technique guide for helping staff through their working day in emergency departments and beyond.

https://www.mind.org.uk/media/26493068/tcoy_tips_technique_guide_online.pdf

Health for Health Professionals Wales is a free, confidential service now available to all Health Professionals and Healthcare Students working in NHS Wales.

https://www.hhpwales.co.uk/

10.   Bereavement

Bereavement is associated with elevated risks to mental health, morbidity and mortality and services that provide bereavement support can be vital in managing these risks. Bereavement support can also reduce the emotional, physical and mental impact of grief.

The impact that the death of a loved one can have on individuals and families, particlarly in light of the constraints placed upon us by COVID-19 cannot be underestimated. Grief is a natural part of our response to death but without our ability to visit loved ones at end of life, or to undertake our usual rituals and practices, that grief experience can become more complex.

The bereavement response has therefore focussed on ways to help families continue as far as possible to maintain contact with those who are in hospital, hospices or care homes by providing technology to support virtual visiting. Hospital visiting guidance has also been isssued by the Chief Nursing Officer to ensure a relative of those at end of life can have limited visits and regulations of funeral attendance have been relaxed to allow the size of the venue to determine how many can attend safely and for family members themselves to determine who those people should be.

Voluntary and third sector providers have a vital role in supporting our communities through bereavement and we have worked with our hospices and bereavement providers to increase the level of support available:

Hospices offer information and support to the family and friends of people who are cared for by the hospice - both before and after a death. Some hospices will work with people who have not had previous contact with a hospice while many work closely with schools to offer advice to teachers. Information and resources can be found on the Hospice UK website:

https://www.hospiceuk.org/what-we-offer/clinical-and-care-support/bereavement

Cruse Bereavement Care offer support, advice and information to children, young people and adults. They have increased their capacity in their telephone helpline and online resources. They have also published advice on dealing with grief and bereavement during the COVID-19:

https://www.cruse.org.uk/get-help/local-services/wales/wales

https://www.cruse.org.uk/get-help/coronavirus-dealing-bereavement-and-grief

Further information about bereavement or counselling services can be found on health board and/or local authority websites.

11. Research and related opportunities

The Marie Curie Research Centre at Cardiff University is currently supporting the following COVID-19 related palliative care research projects:

Rapid bereavement review: Rapid review of the literature of bereavement support at a time of mass death (Marie Curie Research Centre)

Bereavement Survey: as part of a public health survey – on public attitudes to COVID-19 (Wales). Linked qualitative study to interview bereaved families about their perceptions of their relatives EOL care, and their grief reactions

Rapid Review: Symptom burden of patients dying from coronavirus (Marie Curie Research Centre in collaboration)

COVID Confessional: Development of anonymised digital repository for healthcare professionals to offload without fear or recrimination about their daily experiences at the frontline of working through the coronavirus pandemic.

COVID NCRI (National Cancer Research Institute) leadership and collaborative work. Themes for research:

1.   Clinician communication programme/package to guide consultation
2.   Effects on staff regarding patient treatment decisions
3.   Bereavement effects
a)   Not seeing families until last day of life
b)   Not being able to grieve/ grieving delayed or affected by not attending funeral

COVID UK collaborations
Irene Higginson group. Collaborative project rapidly evaluating across the UK the palliative care and end of life care response in COVID-19.

13.   Information Resource

Further frameworks and tools to assist in the management care plans for patients presenting with COVID-19 symptoms are listed below

- The Clinical Frailty Scoring Tool used to support clinical decision making about pathways of care Clinical frailty scale:

  https://www.nice.org.uk/guidance/ng159/resources/clinical-frailty-scale-pdf-8712262765

- NICE Guidance on admission to hospital during Coronavirus:

  https://www.nice.org.uk/guidance/ng159/chapter/1-Admission-to-hospital

- Remote assessment guidance BMJ:

  https://www.bmj.com/content/368/bmj.m1182

- All Wales Care Decisions Tool for End of Life Care:

  https://www.wales.pallcare.info/files/docs/Care%20Decisions%20Toolkit/A-D%20docs%20Generic%20Care%20Decisions%20v10%20%20June%202019.pdf

- Guidance for NHS and social care staff to check if a COVID-19 patient has an attorney or deputy:

  https://www.gov.uk/guidance/nhs-staff-searching-our-registers-of-attorneys-and-deputies